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Social care technologies for older people: evidence for instigating a broader and more inclusive dialogue

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Social Care Technologies for older people: evidence for instigating a broader and more inclusive dialogue

Abstract:

The social care context is changing in many Organisation for Economic Co-operation and Development countries due to demand pressures. In this changing context, social care digital technologies are increasingly championed as a way to support the social care of older adults.

We argue that if social care digital technologies are going to benefit older adult social care users then a broader discussion about how social care is received and provided needs to take place. We believe if this broader dialogue does not take place then it is unlikely that policy ambitions about digital technologies ‘transforming’ social care will be realised. In fact, in this scenario it is unlikely that technologies will meet the social care needs of older adults and could actually exacerbate existing issues.

In the paper we draw on the policy context and the evidence base for social care technologies and their limitations to support this argument. We conclude by signposting current work underway to instigate a broader and more inclusive dialogue around social care digital technologies.

Keywords: Technology, Digital, Social Care, Society, Older Adults

1.1 Argument outline

Undoubtedly in a digital world technology will inform social care. In the last few years, in countries like the United Kingdom (UK), there has been a noticeable promotion of the benefits of social care technologies. The English Local Government Association [1] commissioned a report that laid out proposals for how this technology might be used; some of the language used in this report is instructive. Information and digital technologies are described as ‘transformative’, ‘enabling’, ‘source of improvements’, ‘saving time and money’, and ‘improving purposeful engagement’. A similar appraisal is promoted in a recent report from the Kings Fund [2]. The social care context is also changing. Services in many parts of the world are supporting greater numbers of elderly people with increasingly complex needs but often with sustained reductions in funding, or slow growth in additional funds [1, 3, 4]. It is in this cauldron of the availability of new digital technologies, a growing number of older adults and reduced, or static resources for social care, that the use of digital technology in care has taken on importance.

Knowledge transfer and public engagement in research is a UK government priority [5] but this agenda is not readily apparent in the social care technology field. In her You Tube video, Darling [6] asserted that the ethics of how robots are used is actually the ethics of people and how they relate to each other. We believe this argument is applicable to the whole gamut of social care technologies. Although several of the moral dilemmas involved in the deployment of social care technologies are discussed in the literature, we contend there is a need for fuller consideration of these dilemmas by policy makers and researchers [7]. For instance: What are the implications of placing elders in a position where they are ‘cared for’ by technology devices? [8] If social care digital technologies do not provide as good assistance as people [9], is it right that limited resources are invested in devices instead of the social care workforce? [8] Whose interests are being served: the people who are caring, the people who are being cared for or the market?

We argue that the focus of discussions needs to expand from the current consideration of specific technology implementations to a broader debate concerning how social care is received and provided, and within this debate the place of social care technology. If this broader debate is absent we believe that at best digital technology will undertake social care tasks: it will not meet social care needs, or address inequities. In fact, if there is not concomitant enhanced investment in the social care sector and workforce, an unintended consequence may be that digital technologies exacerbate existing problems. In this paper we present our rationale and evidence for this argument. We start with an explanation of our position on social care and how we have sought to evidence our viewpoint.

1.1.1 Standpoint

As researchers working at the interface of social care research, policy and practice, we believe in the value of dialogue based approaches to research and practice development in the social care sector. Informed by both research and practice we maintain that human relationships are paramount in social care across the life course [e.g. 10-13]. We also believe that human relationships are important for the social care workforce because giving care often has value for the caregiver [14]. We adhere to the position that protecting autonomy and upholding the right to human relationships is integral to treating older social care users with dignity [15]. Our belief that the relational aspects of social care are fundamental underscores our argument that community discussion about the value, worth and place of social care digital technologies in care should inform public policy.

1.1.2 Sources of evidence

To inform this paper, articles published in English were sourced from Medline (EBSCO), CINAHL (EBSCO), PsychINFO (ProQuest), Social Science Premium Collection (ProQuest), British Library Social Welfare Portal and the EThOS database. No date restrictions were applied but only papers published in English were retrieved. Relevant reviews, quantitative, qualitative and process analysis papers as well as discussion pieces were reviewed if they discussed digital technology use in social care. We include discussion papers as sources of evidence because these pieces demonstrate emergent thinking around societal, ethical and moral issues. Additionally a hand search of Technology and Society was conducted from the year 2000 to the present day. This date restriction was applied because of the significant developments in digital technology during the last 18 years. Policy documents were also reviewed.

2.1 Context

2.1.1 Social change and technology

Since the 1990s there has been an acceleration in how digital and information technology is shaping the contours of society and peoples' lives [1, 7, 16, 17]:

The growing integration between minds and machines, including the DNA machine is cancelling what Bruce Mazlish calls the “fourth discontinuity” (the one between humans and machines), fundamentally altering the way we are born, we live, we learn, we work, we produce, we consume, we dream, we fight, or we die [16, p.31]

The internet is an example of a technological development that has profoundly reshaped communications and human connectedness. There is also an increasingly compressed time period between technological innovations and their use in practical terms [17]. This is evident in the uptake and spread of mobile phone applications [18].

Focusing on elderly members of society, in the UK many older adults use digital technology and future cohorts are likely to be vociferous consumers as they will be familiar with a variety of technologies, having used them in their working life [19] and incorporated them into their daily activities [20]. For instance, in the UK amongst people currently aged 45-54 years, 68% use internet banking and 43% make telephone or video calls via the internet [21]. Furthermore, as early as 2009, people aged 65 and over spent more time per month on the internet than any other age group [19] and this trend is continuing [22].

Innovations in social care digital technologies are also developing at pace. For instance, whilst first generation telecare used triggered alarms and second generation telecare used sensors that detected specific hazards, third generation telecare envisages undertaking lifestyle monitoring with data sent to internet portals for caregiver monitoring [23]. Another example are social commitment robots (robotic devices which support social interaction), which have become the commonest form of social care technology to support social contact [24].

2.1.2 Public policy context

One policy conceptualisation of 21st century technologies is that they will reduce strain on services by enabling more self-care [25-27] and hence transform services and ‘solve the social care crisis’ [28]. For instance, one ambition articulated by local government is that digital technology is an integral part of future social care provision [1, 19]. Indeed, some commentators, e.g. Alston [29] contend that a digital welfare state is already emerging with people primarily interacting with authorities online. For instance, by 2016 approximately 36% of UK councils were already offering ways to engage with professionals through digital channels [1]. Wales, which has a devolved assembly and is the context in which the authors work, also intends to make digital technology the ‘norm’ to improve social care delivery [27, 30]. Such policies are not unique to the UK, for example, the Australian Department for Health is trialling innovative digital care technologies and robotic technology is appearing in some areas [31, 32].

However, there are policy tensions about how this ‘technological transformation’ can be enabled given the current organisation and delivery of care services in the neo-liberal welfare state. For example, the protection of data created and collected by technology is a key concern. Encryption of personal data is mandated in international and national legislation, but regulation of social care technologies appears lax [14] as devices are often uncertified (because they are not classed as medical products). This often means that devices are not required to meet stringent privacy standards [33]. The role of the market in social care is also a consideration: some argue that current technology manifestos are aligned with maximising the self-funding of care [14]. Others claim that the market and commercial profit maximising considerations are currently the main driver of digital innovation. It has been noted that narratives around digital technologies often emphasise cost savings [34] and because of the uneven distribution of wealth, such conversations awaken concerns regarding social justice [33].

The policy context is important because it has tangible impacts on practice. For instance, when telecare operators were asked to co-design a new operating system they were influenced by the dominant political narrative and devised a system based on episodic care despite their understanding that continuity of care and ongoing relationships were important [35]. Debating care devices in market terms also makes it easier to construe technology as a

replacement to human care rather than as a supplement [8]. Currently carers and elderly social care users have limited power to inform policy and this creates a real potential for technologies to disable rather than empower [13].

3.1 Evidence base

Although high quality research about social care technology is lacking [36, 37] the current evidence base gives some grounds for believing that digital technology, as a part of social care provision, will be beneficial:

- Devices can improve activity participation in community-dwelling people with dementia [38]
- Positive outcomes have been found for technologies that support orientation, medication compliance, hand washing and activity planning in supported living and residential care [15]
- A synthesis of studies exploring assistive technology for cognition across a range of users found that 67% of studies reported positive outcomes [39]
- A review of devices facilitating real time contact reported positive findings [40]
- Simulated presence therapies generally enhance wellbeing and reduce disruptive behaviours [15]
- In people with dementia, there is some evidence that social commitment robots are effective at reducing social isolation and enhancing emotional wellbeing [41, 42]
- Telecare systems can provide users and carers with a sense of safety and security and this can reduce caregiver stress and burden [43]

Furthermore, everyday digital devices have been shown to reduce social isolation and enhance wellbeing [42]. For instance, reliable broadband can reduce the social isolation of rural dwelling housebound elderly and enhance independence [1].

3.1.1 Receptiveness to technology

Optimism can also be drawn from studies that show, in general, that older people have a positive inclination to technology [44]. An American survey of elders aged 65 years and over found that they saw technology as a positive way to improve quality of life [45]. Elders have even expressed a desire for self-initiating social technologies [40], which inherently diminish users' control. Similarly there is little evidence that elders are concerned about devices that mimic 'real beings' and little evidence that elders are deceived about the nature of such devices [46]. Some may in fact be comfortable with devices they can anthropomorphise like other tools [24, 40]. Ethnographic studies confirm that elders are using devices to assist them with daily tasks and connect with others [12].

Concerns that technologies could create a 'dehumanised society' are expressed primarily by people who lack direct experience with devices [24]. Actual experience with technology can induce more positive attitudes [e.g. 47], perhaps because people gain confidence in it [44, 48]. This is the case even though most social care technologies are supplied after acute events [13], a scenario which could foster negative perceptions. This phenomenon is particularly evident when people interact with more novel technologies, such as social commitment robots [24, 40]. When concerns remain these are often based on the assumption that technologies will replace (rather than complement) human support. For instance, caregivers were critical of an assistive device because they considered themselves "irreplaceable" [11].

This receptiveness might be because many elders have a similar narrative to policy makers and technology designers: a narrative that values living ‘independently’ [8]. Working within this narrative, designers have taken an instrumental approach, emphasising task based care, productivity and efficiency. Similarly, elders, informed by the same narrative, have viewed technologies as useful because of their assistive or entertainment functions [24, 34], with only some perceiving the inability of social technologies to share emotion as a barrier [11].

3.1.2 Bricolage

Elderly social care users and their carers (paid and unpaid) seem adept at customising technologies to suit their needs [49]. Ethnographic studies indicate that the most accepted and useful devices are those that require little effort to incorporate into existing routines [12, 44], especially those that do not need specialist knowledge [50]. This may be why devices based on familiar technologies are well accepted [12]. Several writers have concluded that technologies should design in adaptability as well as substitutability and interoperability [e.g. 24, 33, 51]. This is also imperative for economic reasons: even at a sub-population level there is limited consensus about what properties technologies should have [47].

This level of technological personalisation is not being achieved purely through device design, it is the outcome of elders and their carers working together. Assistance from carers alongside user insight and creativity is required [49] as adaptations need to continually evolve alongside changing circumstances. This translates into evidence that if the right human ingredients are present in the social care context, digital technologies can enhance social care: elder and family co-produced devices can assist with care delivery and help maintain wellbeing [1].

3.1.3 Workforce uptake

Examples of successful bricolage also offer evidence of the ability of the social care workforce (given the right resources and support) to support elderly social care digital technology users. Numerous research studies attest that care staff can suggest ways to optimally integrate technology into social care. One example of such a study is the work by van Hoof et al. [52]. They asked staff working in nursing homes (as well as technology designers and construction sector workers) to identify the important aspects to consider when designing new nursing homes. The findings indicated that technologies should be user friendly, integrated into the environment and serve the needs of residents and staff. All technologies must be easy to understand and use and should not need a skilled technician. The importance of insights from the workforce is recognised by UK local government, which is increasingly involving the workforce in developing digital provision. For instance, in 2016, 80% of UK councils had engaged lead social work practitioners in their digital strategy [1].

4.1 Limitations of technology

There is little published evidence that digital technology is currently having a detrimental effect on elderly social care users. The few exceptions are a sensor device that residents could not apply independently, leading to excess disability [53], a social commitment robot becoming an additional ‘responsibility’ and a source of anxiety [54], and some families finding social commitment robots challenging to use [15]. However, technologies have not been deployed at scale and absence of evidence does not equate to absence of harm. For instance, although Huber et al. [55] found that technology had no effect on the frequency of contact with unpaid carers, all participants in this small study had pre-existing supportive relationships. It is easy to see that this finding might not generalise to all elderly social care users.

It is also possible that once technologies are deployed at scale over a longer time period more equivocal evidence may be found as more data accumulates. For instance, telecare has been an available technology for some time. One large cluster trial of second generation telecare demonstrated that compared to standard care (which included first generation telecare) for people with social care needs, the addition of second generation telecare was not cost effective [56]. In a recent review of mainly first generation and some second generation telecare, there was no clear evidence that these systems prevented or delayed institutionalisation [23]. However, one reason for the problems with telecare may be its particular limitations on what bricolage/ personalisation is possible: it often only works in the home, which can limit opportunities for active aging [23]. Technologies which do not integrate well with human care may have less potential.

The main causes for current concern apparent in the literature relate to the fundamental nature of care, the need for real choice, underinvestment in social care, non-universal receptiveness and digital inequalities. Each of these factors are now discussed.

4.1.1 Care fundamentals

Although the dominate discourse in western societies prizes independence and autonomy [13], within the social care sector there is a strong narrative that people are fundamentally relational beings and interdependent on one another [10]. It is arguable in fact that when elders talk about independence they are actually referring to interdependence, where reliance on others is balanced by their own contributions to these relationships [57]. There are several circumstances where, if technologies do replace carers in even a few tasks [14], elders might be at greater risk of social isolation [8]. For instance, although telecare gives the impression of more immediacy, it actually introduces greater distance into the care process [35]. Furthermore, the mere presence of technology may impact on the quality of continuing human interactions. For instance, in a study by Kramer, Friedman and Bernstein [58], unaccompanied visitors were paid more attention than visitors accompanied by a social commitment robot. Furthermore, visitors initiated less conversation when accompanied by the robot.

There may be other insidious consequences of increased dependence on digital technologies. As a UNESCO report [32] warned, technologies may influence the value framework on which care is based. It is unlikely that technology will ever be able to provide truly relational care [8, 54] and so the value framework for care will inevitable change. However, devices' lack of empathy and affect arguably deprive elders of the necessary pre-requisites for developing the sense of self-recognition, respect and mutuality which are common benefits of entering into relationships [8]. There are also the implications of elders becoming emotionally 'attached' to their digital devices to consider [32].

When human contact is available most people respond more to the person even if a technology device is present [41, 58]. The relational aspects underpinning care are so ubiquitous that we argue they have confounded many studies: most researchers have not considered human interaction as a confounding variable [24]. For instance, social commitment robot sessions are often delivered by trained staff to groups of elders [59]. When one study asked participants what they liked about these sessions, nearly half replied the social gathering and observations also suggested that these sessions are enjoyed primarily for their human social aspects [46]. Similarly, a lot of the benefits of telecare are the result of human work not the devices [35].

4.1.2 Real choice

To remain autonomous elders must consent to the use of technology in their care [15]. However, informed consent is going to become progressively difficult to establish because technologies are emergent, meaning that the circumstances, nature and outcomes of device use cannot be completely known [14, 24]. There are also concerns that technologies may insidiously reduce independence [14, 24, 44] in a way that it will be difficult to consent to. Therefore, over time elders will paradoxically need to consent to relinquishing some autonomy over their care and daily life as this is the basis on which ambient technologies increasingly operate [14]: often the elder's only role in a sensory based system is to act as a trigger [53]. It is arguably difficult for people to make a 'real choice' as these devices are already influencing care processes and becoming part of the care context [8]. For example, devices are starting to impact on the psychosocial milieu [59] through the cultural values instilled in their operating algorithms [49] that ascribe roles to device users and care providers [24].

Increasingly it will not just be the user of social care digital devices who needs to consent: these technologies will likely impinge on the lives of co-habitants and others [14]. It must also be remembered that family members, friends and neighbours provide care alongside paid workers. These unpaid carers need to make an informed choice about whether they use social care digital devices: some argue [e.g. 60] that devices are likely to increase demands on unpaid carers, even though these individuals often engage with technology to try and reduce their care burden [35].

A further related issue is where accountability and responsibility for technologies should rest [8, 32]. Unpaid carers have raised concern about their legal liabilities if a technology becomes misused [14] and this concern might be particularly pertinent in community care, where the 'safety nets' that operate in institutional environments are lacking [14]. Accountability will only become more challenging as technologies approach the point of adapting autonomously to emergent situations [14, 32].

Fundamentally, if elders are to have genuine choice, society needs to demand that equally effective care is afforded to people who refuse technology based assistance [14, 61] and this could prove difficult and costly if technology based care becomes the 'norm'. For instance, telecare has sometimes been withdrawn in a somewhat punitive manner if elders have been reluctant to engage [23].

4.1.3 Underinvestment in social care

We have provided evidence that the social care workforce has a critical role in supporting digital technology uptake [1], but before they can fulfil this role at scale they need access to support and training to learn how to work alongside technologies [14, 27, 35]. Given the pace of technology development [19], the care workforce will need regularly updated information about what devices are available, their criteria for use [12] and how they can be implemented [50]. Not all social care staff are as positive about technology or as skilled in its use as in the studies previously referenced. For example, in a study exploring the use of dynamic lighting systems in care homes, managers actually thought care staff should not have a role in operating the system as this would risk the implementation. Likewise some staff did not want a role in maintaining the system as they did not see this as their responsibility. Carers were also concerned about the system's influence on their own circadian rhythms [62] and the

safety of carers working alongside digital devices is an area that demands further consideration [32].

Elders can expect care staff to teach them how to use devices [24] and lacking this input can prevent adoption [44, 61]. However, even after training many elders only achieve limited understanding of devices [13, 23] and ongoing support is essential [49]. Although some support could be provided through the emerging technician workforce [14], given the intimate nature of the support and degree of personal knowledge required, care staff will arguably remain best placed to provide assistance. For instance, task performance is often impinged by non-specific impairments [49]: user distress or agitation (rather than a performance deficit) is a common cause of task failure [33]. Technologies are unlikely to be able to compensate for these motivational impairments [13] and may struggle to accommodate other non-specific impairments like sensory deficits [19]. They may also be unable to adapt to deteriorating conditions [12]. Furthermore, few current devices can support the types of complex behaviours that elders depend on daily: a synthesis found no technologies which assisted users with psychomotor functions, perceptual functions, language or sequencing [39]. This underlines the continued need for human support alongside devices to enable good care and the need for investment in the workforce.

4.1.4 Non-universal receptiveness

Despite the points raised earlier, technology adoption is not universally high. Initial reservations are common [15, 47, 61] with concerns often expressed about privacy, safety and security [14], autonomy, non-maleficence and beneficence [33]. Greenhalgh et al. [13] contend that there is a concern within some of the older population about how technologies will impact on their functioning and autonomy. For instance, concern about stigma has been cited in 18% of studies [44] and there is a clear consensus that elders do not want devices perceived as infantilizing [e.g. 63]. Furthermore, elders and their families are reluctant to accept technologies which change the look of the home and so communicate needs to others [12, 24, 43, 47]. In the research it is interesting and notable that most people endorse social commitment robots for others but not for themselves [24]. Causes of technology ambivalence may be subtle: some have argued that the visible presence of devices might evoke feelings of 'being old' [24] and may be perceived to herald institutionalisation or death [13].

In fact the current evidence may lead to an unrealistically optimistic appraisal of receptiveness as attitudinal data has typically been collected from elders participating in technology trials. These respondents are more likely to be receptive to technology and misgivings in the general elderly population may be more strident [51]. For instance, a large European survey found that more hostile attitudes towards robotic elder care were expressed by women, people with less formal education and skilled employment, and people living in less densely populated areas [64]. Process data may also be informative. In trials of social commitment robots, a degree of refusal and attrition is common [46, 59, 63] despite the fact that sometimes participants have to demonstrate an interest in the device to participate [59].

4.1.5 Digital inequalities

Government policies often assume that people are competent with digital technologies but many poorer and vulnerable sections of society are effectively offline and without digital skills [29]. In an American survey of older adults nearly half the respondents had not learnt technology skills and the majority had experienced difficulty when using digital devices. It was the respondents with more education who were more positive about technology and more willing to learn about it [45]. It is also self-evident that within society, some members will

find the purchase and running costs of technologies prohibitive [19]. Lacking access to technology can already arouse feelings of alienation [14, 17] and some writers contend that current advances in everyday technologies and how these have been distributed across society have already contributed to digital divides and exclusion [34]. If this situation continues elders will become progressively more disengaged from society as they fail to move up the technology adoption curve [45].

The digital divide occurs across societies as well as within them. A recent review found that the potential for universal access had only been considered in five intelligent assistive technologies [33] highlighting that, globally, rather than enabling more people to access social care, technologies may simply give more resources to societies which already have better provision. So technology use in social care will only serve equality if there is an impetus for low cost devices and open designs [33].

5.1 Concluding comments

We have argued that to ensure the promises and benefits of social care digital technologies are realised, their use has to be situated in an understanding of the importance of relational care and people's interdependence. We have also argued that there needs to be parallel investment in the social care sector to equip the workforce to incorporate new technologies into their work in a way that is beneficial to the individual needs of elderly service users. We have presented evidence that some of the foundations for successful adoption of digital social care technologies are already in place. However, we have also presented evidence that there are impediments to making the most effective and equitable use of these devices. In contemporary UK social care policy the language and principle of co-production has gained prominence. Rather than a blind move ahead to invest in digital social care technologies we have argued for a wider societal discussion about the challenges, promises and dilemmas presented by these matters. Consistent with the principles of co-production, this discussion should be an inclusive one, most importantly including elderly social care users themselves but also including the public and paid and unpaid carers. This is fundamentally a debate about how care is afforded to elderly members of society and the role of technology within it. It is a debate about the ethics of care, and where we are headed as a caring society [5, 32].

Here is just one example of the sort of community debate that might materialise. When outlining our argument we suggested that a key question concerns who should derive most benefit from social care digital technologies. Different answers to this question will have myriad impacts for resource allocation, device design and use. For instance, there are inherent tensions between safety and privacy [24], so should devices give precedence to safety or privacy? People with dementia often want more direct control over devices (enabling more privacy) but caregivers sometimes argue against this [14]. Similarly, elders are often prepared to take risks to achieve their goals, whereas carers can be risk adverse [13, 53]. Community dialogue may forge a way towards finding a compromise that accommodates these different stakeholder interests.

We are embarking on a programme of work that we hope will ignite a wider community discussion. The first step is a Delphi study where we hope to include elderly social care users in determining the priorities for social care technologies. The Delphi study will also include the voice of other stakeholders seldom reflected in the literature, including care providers, commissioners, care staff and unpaid carers. We do not anticipate easy or clear answers as conceptualisations of social issues and values vary. For instance, there are various constructions of trust, autonomy, relational care and interdependence [48] and it may be

difficult to decipher if different stakeholders are talking about the same concepts. However, we believe the value will be derived from the dialogue based approach that starts to engage a wider audience in the discussion.

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